

based on a rejection of the hospital-based, medical model of delivery.

The breakdown of out-of-hospital births by location, characteristics of mother, use of health services, and characteristics of the infant has revealed differences between black and white groups as well as considerable change for each group over time. While the implications for the safety of planned home births must, given the approach used here, remain tentative, the group differentials in themselves and the patterns of change warrant careful attention.

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Where Cancer Patients Die: An Epidemiologic Study

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SYNOPSIS

In a sample of deaths among cancer patients, the relationship of place of death to age, sex, length of time between diagnosis and death, cancer site, and patients' socioeconomic status was investigated. The Rochester (N.Y.) Regional Tumor Registry provided these data for all cancer patients who died in Monroe County, N.Y., during 1976, 1977, and 1978. Patients who had not been residents of the county were excluded from the sample, as were patients

under 15 years of age at death and those whose cancers had been diagnosed only at autopsy.

Analysis with a logit model was used to estimate odds ratios that compared the probabilities of death in an acute care hospital and in a chronic care facility with the probability of death at home. Patients whose cancers had been diagnosed less than 1 month before their deaths were significantly more likely to die in a hospital than were patients whose cancers had been diagnosed earlier. Cancer sites, too, were significantly related to place of death: persons with leukemia or lymphoma were most likely to die in a hospital, followed by patients with lung, breast, and upper gastrointestinal tract cancers; persons with colorectal, genitourinary, and miscellaneous cancers were most likely to die at home.

The patients whose deaths were studied were classified by socioeconomic area (SEA) ranking. Patients who had resided in higher level SEAs were more likely to die at home than those from lower level SEAs; however, this trend was reversed among patients from the lowest level SEAs, who had a relatively high rate of death at home and a low rate of death in chronic care facilities.

IN RECENT YEARS THERE HAS BEEN A SURGE of interest in the quality of care of the dying in this country, and in the costs of such care (1,2). The hospice movement has begun to affect patterns of caring for the terminally ill, both directly, through the provision of various models of hospice care, and indirectly, by creating awareness of the problem among the medical community and the general public. Cancer patients have been the main target for this concern. They constitute the majority of patients for whom the hospice type of care appears appropriate, but it is likely that patients with various other diagnoses may benefit equally from improvements in terminal care.

During the last 30 years or so, there has been a national increase in the proportion of deaths in institutions and a corresponding decrease in the proportion of deaths at home. A review of deaths from cancer in Cuyahoga County, Ohio, from 1957 through 1974 indicated that while the rate of death in hospitals stayed fairly stable, at about 64 percent of the total, the rate of death in nursing homes increased from 7 to 20 percent and the rate of death at home decreased from 30 to 15 percent (3). The shift from deaths at home to deaths in nursing homes presumably reflects the establishment of Medicare and Medicaid in 1965 (4).

In some communities, there are signs of a reversal of this trend. For example, in Monroe County, N.Y., the percentage of cancer deaths that took place at home increased from 17 in 1977 to 25 in 1979 (data provided by the Rochester Regional Tumor Registry). One factor that may contribute to this recent trend toward death at home is the tremendous expansion in use of home health services—particularly among the elderly—that followed the Social Security Act amendments of 1972 (5).

In view of these significant developments in terminal care, there has been remarkably little research in this country on what Brody (6) has termed “the epidemiology of the last days of life”: population-based studies of the process of dying and of determinants of different patterns of care during this period. Several such studies have been reported from the United Kingdom (7,8), but there are important differences in patterns of terminal care that limit their applicability to this country.

Place of death is one aspect of the process of dying that seems to deserve further study. It is an indicator of place of care during the terminal period of life, although a tendency has been noted for some individuals, who have been cared for primarily

at home during the terminal period, to be admitted to a hospital during the 2 weeks before death.

Factors related to hospitalization of the terminally ill patient can be grouped into medical and social indications for admission. Medical indications for admission (usually to an acute care hospital) include management of pain and other symptoms, performance of a surgical procedure or administration of other treatments, and diagnostic evaluation (9,10). It should be realized that not all terminally ill patients will be receiving palliative therapy. Some will be receiving some form of active, tumor-directed therapy, including cytotoxic chemotherapy or radiotherapy. Others, for whom the diagnosis of cancer was only recently made, may be undergoing further diagnostic or pretreatment evaluation. Social indications for admission (either to an acute care hospital or to a chronic care facility) include absence of a family member or another person to act as the primary care giver in the home, need to provide temporary relief for the care giver (respite care), or financial reasons related to peculiarities of the patient's health insurance benefits (9-12).

The study described here took place in Monroe County, N.Y., as one of a series of studies of the epidemiology of terminal cancer care conducted by the Epidemiology Unit of the University of Rochester Cancer Center. Monroe County is an interesting site for such a study, and in some ways is atypical of the country as a whole. The county has a highly developed system of home health services, and the Rochester Blue Cross plan was the first in the nation to offer a home-hospice reimbursement package to terminally ill patients, as a result of a pilot demonstration in 1977. In addition, the cancer center, decentralized into oncology units at each of the county's five major acute care hospitals, provides an unusually high level of medical care for cancer patients in the community. The objectives

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of the study were to determine place of death in a series of cancer deaths in Monroe County and to assess the relationship of place of death to age, sex, ethnic group, length of time between diagnosis and death, cancer site, and patients' socioeconomic status.

Methods

The Rochester Regional Tumor Registry (RRTR) receives reports of new diagnoses of malignant neoplasms from Monroe County and from several surrounding counties and reports these cases to the New York State Cancer Registry. Comparison of the two registries indicates that RRTR is notified of virtually all malignant neoplasms reported before death in patients resident in Monroe County. Since 1976, RRTR has routinely computer-matched its case records against the death records kept by the New York State Health Department's Bureau of Vital Statistics. In addition, RRTR receives death reports from other sources.

In spring 1980, a data set for deceased cancer patients was compiled by RRTR for the years 1976, 1977, and 1978 (the most recent years for which reports of cancer incidence and cancer death were believed to be complete). Deceased patients were included in the study if (a) they had died in Monroe County during those years, (b) death was ascribed to a malignant neoplasm, (c) the most recent address for the patient that had been reported to RRTR was in Monroe County, and (d) an incidence report (a report of the diagnosis of the patient's cancer) had been received by RRTR. Persons whose date of cancer diagnosis coincided with date of death were excluded from the study, as were those whose death had been reported by death certificate only, since many of the latter deaths are found on investigation to be unrelated to malignancy.

Data compiled for each patient included place of death, age at death, sex, ethnic group, cancer site, date of diagnosis, and census tract of residence. If only one primary cancer site had been reported for a patient, site was coded as site at diagnosis. If two or more primary sites had been reported, sites were matched against cause of death. If one or more matches were found, date of diagnosis for the first reported matching site was used. If no matches were found, the most recently reported primary site was used.

Census tract data were used to determine patients' socioeconomic areas (SEAs) of residence.

The Wiley-Wagenfeld SEA (described in mimeographed materials in the Department of Preventive, Family, and Rehabilitation Medicine, University of Rochester) was used in this study. Census tracts are ranked on the basis of a five-part composite index derived from the following 1970 census data: median value of owned homes; median rental value; percentage of professional, managerial, sales, and clerical workers; median years of education (of adults); and median family income. Census tracts are grouped into five SEAs, area I representing the highest socioeconomic level and area V the lowest. Cutting points between groups are based on percentiles: SEAs I and V occupy the upper and lower 10 percent limits, SEAs II and IV the next 20 percent, and SEA III the middle 40 percent.

Cases were excluded from further analysis if SEA could not be coded ($N = 76$) or if place of death had not been recorded ($N = 246$). Place of death was grouped into deaths at home, deaths in acute care hospitals, and deaths in chronic care facilities (nursing homes and chronic care hospitals).

Methods of analysis included cross-classification of place of death against each of the independent variables and discrete multivariate analysis, using the logit form of the log-linear model (13).

Results

A total of 2,989 deceased patients met the eligibility criteria for the study. Of these, 17.9 percent had died at home, 69.6 percent in an acute care hospital, and 13.5 percent at a chronic care facility. Table 1 displays place of death by each of the independent variables. With regard to age, there was an approximate sixfold increase in the percentage of deaths at a chronic care facility with increasing age, the major change occurring at age 65 and over. A corresponding decline in the percentage of deaths at an acute care hospital can be seen, with less change in the percentage of home deaths. Sex and ethnic group showed only small associations with place of death: deaths at acute care hospitals were somewhat more frequent among males than among females and among blacks than among whites.

The relationship found between SEA and place of death was not a simple one. If SEAs I to IV are considered, there was a trend toward an increasing percentage of home deaths in the higher SEAs, with corresponding declines in both categories of institutional death. SEA V showed a different pattern, with a relatively high percentage of home deaths (20.8

Table 1. Place of death of Monroe County, N.Y., cancer patients, 1976-78, by independent variables studied

Variable	Number	Percent	Percent dying at		
			Home	Acute care hospital	Chronic care facility
Total	2,989	100.0	16.9	69.6	13.5
Age at death:					
15-54	535	17.9	17.6	78.1	4.3
55-64	674	22.5	17.2	77.7	5.0
65-74	846	28.3	18.4	68.7	12.9
75 or more	934	31.2	14.8	59.7	25.5
Sex:					
Male	1,482	49.6	16.6	72.2	11.2
Female	1,507	50.4	17.1	67.1	15.8
Ethnic group:					
White	2,840	95.0	17.0	69.6	13.5
Black	128	4.3	14.8	71.9	13.3
Other or unknown	21	0.7	14.3	61.9	23.8
Socioeconomic area:¹					
I (highest 10 percent)	446	14.9	20.2	66.4	13.5
II (next highest 20 percent)	969	32.4	17.9	71.4	10.7
III (middle 40 percent)	1,175	39.3	15.7	68.3	15.9
IV (next lowest 20 percent)	303	10.1	11.9	72.9	15.2
V (lowest 10 percent)	96	3.2	20.8	71.9	7.3
Cancer site:					
Colorectal	461	15.4	20.4	60.3	19.3
Lung	612	20.5	15.2	75.3	9.6
Breast	313	10.5	17.9	67.7	14.4
Genitourinary	480	16.1	20.4	63.5	16.0
Leukemia, lymphoma	315	10.5	10.5	81.6	7.9
Other gastrointestinal	371	12.4	14.3	74.4	11.3
Other	437	14.6	17.6	67.0	15.3
Length of time between diagnosis and death:					
Less than 1 month	318	10.6	4.7	91.2	4.1
1-3 months	390	13.0	15.4	70.3	14.4
3-12 months	818	27.4	18.2	67.4	14.4
1-2 years	465	15.6	21.9	65.8	12.3
3-4 years	456	15.3	20.8	66.9	12.3
More than 4 years	542	18.1	15.3	65.5	19.9

¹ See text for explanation.

percent) and a very low percentage of deaths at chronic care facilities (7.3 percent).

Cancer site also appeared to be related to place of death, with approximately twofold differences in the risk of home death by site. Patients in the leukemia and lymphoma group had the highest rate of death at acute care hospitals (81.6 percent) and the lowest rate of death at home (10.5 percent). Patients with colorectal and genitourinary cancers had the lowest rate of death in acute care hospitals (just over 60 percent) and the highest rate of death at home (20 percent).

Length of time between diagnosis and death bore a striking relationship to place of death. More than

90 percent of patients whose cancers had been diagnosed less than a month before death died in acute care hospitals, compared with 65 to 70 percent of those whose diagnosis had been made a month or more before death. As length of time between diagnosis and death increased to 4 years, so did the percentage of patients dying at home. For patients who lived more than 4 years after diagnosis of their cancers, however, the percentage of deaths at home declined, while that of deaths at chronic care facilities rose.

Initial analysis with the logit model used all the variables listed in table 1 except for ethnic group, which was excluded because of the small number

Table 2. Estimates of effect, odds ratios, and standardized ratios for logit model, comparing cancer deaths at acute care hospitals and chronic care facilities with deaths at home¹

Variable	Acute care hospital			Chronic care facility		
	Estimate of effect	Odds ratio	Standardized ratio	Estimate of effect	Odds ratio	Standardized ratio
Site:						
Colorectal	0.00	1.00	...	0.00	1.00	...
Lung	0.24	1.27	2.11	-0.22	0.80	1.57
Breast	0.28	1.32	2.09	-0.09	0.92	0.52
Genitourinary	0.10	1.11	0.88	-0.06	0.94	0.44
Leukemia, lymphoma	0.94	2.56	6.10	-0.09	0.91	0.46
Other gastrointestinal	0.36	1.43	2.75	-0.18	0.84	1.10
Other	-0.03	0.97	0.28	-0.16	0.85	1.10
Length of time between diagnosis and death:						
Less than 1 month	0.00	1.00	...	0.00	1.00	...
1-12 months	-1.68	0.19	10.63	-0.18	0.84	0.90
1-4 years	-1.90	0.15	11.73	-0.50	0.61	2.42
More than 4 years	-1.82	0.16	10.34	-0.15	0.86	0.68
Socioeconomic area:						
High (I, II)	0.00	1.00	...	0.00	1.00	...
Medium to low (III, IV, V)	0.20	1.23	3.04	0.46	1.59	5.48

¹ For each independent variable, the first listed category is the reference category for estimates of effect and odds ratios.

of nonwhites. Significant effects were observed only for cancer site, length of time between diagnosis and death, and socioeconomic area. Thus, in the final analysis age and sex were dropped in order to improve the precision of the estimates. A logit model was fitted that included the following parameters: all main effects, all two-factor interactions, and the three-factor interaction among the three independent variables. All interactions were found to be nonsignificant, and the final model fitted included only the main effects of the independent variables. Fitted frequencies according to this model closely approximated observed frequencies (goodness of fit $\chi_{90}^2 = 98.72$).

Table 2 displays the estimates of effect, odds ratios, and standardized ratios (equivalent to *t* statistics), comparing deaths at acute care hospitals and at chronic care facilities with home deaths. The odds ratios for cancer site and death at an acute care hospital seemed to group into three categories: (a) the leukemia and lymphoma group (patients in this group, when compared with patients with colorectal cancer, were 2.56 times more likely to die in an acute care hospital than to die at home); (b) lung, breast, and other gastrointestinal cancers (odds ratios for death in an acute care hospital between 1.27 and 1.43); and (c) genitourinary, colorectal, and other cancers (corresponding odds ratios between 1.11 and 0.97). The odds ratios for

chronic care facility deaths by cancer site did not differ significantly from unity.

Odds ratios for length of time between diagnosis and death showed the greatest departures from unity. Patients whose cancers had been diagnosed a month or more before their deaths were significantly less likely to have died in an acute care hospital than those whose cancers had been diagnosed a month or less before death. The results can be expressed alternatively as a risk of home death about 5 to 7 times greater for persons in the longer term categories.

Significantly elevated odds ratios were also found for socioeconomic area. Cancer patients from lower level SEAs (III, IV, and V) were somewhat more likely to die in an institutional setting than were those from SEAs I and II (odds ratios of 1.23 and 1.59).

Discussion

The results of this study are notable in that age and sex of the dying cancer patient had relatively little effect on place of death, while length of life after diagnosis, cancer site, and socioeconomic area were all found to have significant effects.

The results suggest that patients who died within 1 month of diagnosis were approximately 5 to 7 times more likely to die in an acute care hospital than those who lived longer. In the case of patients

who lived longer than 1 month after diagnosis, there was little or no consistent relationship between length of time and place of death. This finding is consistent with the expectation that, during the weeks following diagnosis, a cancer patient may spend considerable time in the hospital, undergoing further diagnostic and pretreatment evaluation and receiving treatment. Some of the early deaths may have resulted from the initial treatment that was given. In addition, many of these patients would have been seriously ill at the time their cancer was diagnosed and therefore would have been kept in the hospital. Although the terminal stage of their illness may have been recognized, there may have been insufficient time to organize home care or to arrange for transfer to a chronic care facility.

The results of this study indicate that cancer patients who resided in higher level socioeconomic areas were somewhat more likely than patients who resided in lower level SEAs to die at home rather than in an institution. There was also an indication that patients from the lowest level socioeconomic areas (SEA V) were an exception to this trend, dying at home at rates at least as high as those of patients from SEA I. Unfortunately there were too few patients from SEA V to confirm this finding in a multivariate analysis.

These results are consistent with those reported by Ryder and Ross (1) from a survey in Connecticut. They reported that a greater percentage of dying patients indicated a preference for dying at home than actually achieved that wish: the two groups that achieved the greatest success in dying at home were at the two extremes of socioeconomic status. The upper level socioeconomic group had the help of private health insurance and greater control over monetary and other resources, while the lower level group was eligible for reimbursement of home care services under Medicaid.

Although Medicaid patients may have some advantages in obtaining reimbursement for home care services, they often have difficulties in obtaining admission to nursing homes. Nursing home administrators frequently prefer to admit private-pay rather than Medicaid applicants because they believe Medicaid's reimbursement levels are inadequate (14). This may account, in part, for this study's finding of a very low percentage of SEA V cancer patients who died in chronic care facilities.

The problems of using an area-based rather than an individual measure of socioeconomic status should be noted; however, the effect of any resulting misclassification of patients might be expected

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to be to understate the true risk. It is therefore quite likely that an individual measure of socioeconomic status would have shown a greater association with place of death.

In interpreting the differences in place of death in this study by cancer site, it is important to note that potentially confounding effects of age, sex, and duration of disease have been controlled by means of the multivariate analysis used. There may still be some residual confounding due to socioeconomic status because, as previously noted, an area-based rather than an individual socioeconomic status measure was used. The results may be interpreted by considering aspects of the natural history and treatment of cancers at various sites.

Admission of the cancer patient to a hospital may be for symptoms resulting from particular site-specific patterns of metastasis of the primary tumor. For example, tumors tending to metastasize to bone, such as tumors of the breast, lung, and prostate, may cause more severe and intractable pain (15). Tumors of the genitourinary tract and lower gastrointestinal tracts may give more problems associated with incontinence (10). Symptoms that precipitate admission may also result from medical or surgical treatments. For example, colostomies for colorectal tumors may present specific management problems. Yet another reason for admission may be that a specific cancer site is the subject of clinical investigation. This possibility is more likely to occur in a community with a cancer center that participates in a variety of clinical investigations, including intramural and national collaborative trials. In Monroe County, during the period of this study, there was relatively greater interest in investigation of lung and breast tumors than of those at other sites.

In this study, patients in the leukemia and lymphoma group had the highest rate of death in acute care hospitals. A large percentage of these patients could be expected to be on cytotoxic chemotherapy

(16). This treatment is frequently complicated by infections and bleeding that may require hospital admission (17).

At the other end of the spectrum, with the lowest rate of death in acute care hospitals, were patients with tumors of the genitourinary tract, colon-rectum, and miscellaneous sites. Prostate cancers accounted for the largest percentage of genitourinary tumors. Patients with these tumors and with colorectal tumors are most likely to be treated surgically and then followed in the community; few are referred to the cancer center for further investigation of their tumors.

Analysis of the limited number of variables included in this study has yielded some interesting findings, some tending to confirm previous work and others not previously reported in this context. Important variables that are not included in this study relate to the social supports of the dying cancer patient and to the type and severity of symptoms experienced. Inclusion of these variables could be expected to make it easier to predict place of death on the basis of the patient's characteristics.

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Uterine Cancers of Unspecified Origin— a Reassessment

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SYNOPSIS

Uterine cancer ranks third in cancer incidence and fifth in cancer mortality among American women. The epidemiologic characteristics of cancer of the cervix uteri and the corpus uteri are different. When